



# Autoimmune Disease & COVID-19 Information

National Survey Results & Community Input



Alliance for  
Patient Access

November 2021



# Introduction

Constant and conflicting messages about COVID-19 vaccination leave some autoimmune disease patients uncertain about how to protect themselves.

From rheumatoid arthritis to multiple sclerosis, lupus to pemphigus, autoimmune diseases occur when a person's autoantibodies mistakenly attack their body's own tissues. Some medications for autoimmune diseases suppress the immune system, increasing patients' COVID-19 risk. These people may be more likely to develop serious illness if they contract COVID-19, more likely to spread it to household contacts and more likely to die from COVID-related complications.

When it comes to fully understanding those risks and how to mitigate them, however, awareness lags. A flood of information has left some autoimmune patients confused on critical questions about risk and vaccination.

Through national survey data and insights from key patient advocacy organizations, this report explores the struggles autoimmune patients face — and how policymakers can help.



# Living with Autoimmune Disease

## during COVID-19

### The Pandemic Hits Close to Home for Autoimmune Patients

As people living with autoimmune diseases watched the nation grapple with COVID-19, they also felt its impact in their own day-to-day lives.



78%

Know someone who contracted COVID-19 or caught it themselves

58%

Know a family member or close friend who contracted COVID-19

49%

Know a colleague, neighbor or acquaintance who contracted COVID-19

Autoimmune patients said the pandemic compounded the day-to-day challenges of managing their condition. A majority (61%) reported an emotional toll, such as feeling:

30%

Anxious

16%

Frustrated

15%

Overwhelmed



**“ Because some symptoms of lupus mimic COVID-19, we hear from people with lupus with concerns they’re not sure if their symptoms are COVID-19 or lupus. ”**

– Patrick Wildman  
Lupus Foundation of America

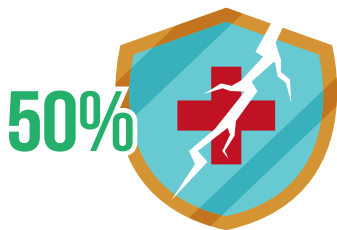
# Understanding the Risks

## Autoimmune Patients Don't Fully Understand their Risks

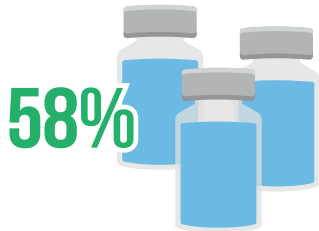
When presented with information that has been issued by the Centers for Disease Control and Prevention, only about half of patients reported being “very aware” that an initial vaccine regimen may not fully protect them and that they may need a third dose to improve their immune response.

### Patient Awareness “Very Aware”

### Statement of Risk



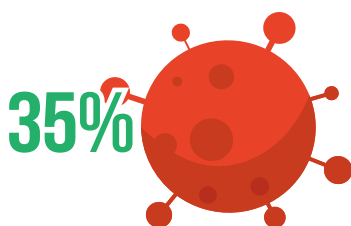
“People taking immunosuppressant medications may not be fully protected from COVID, even if fully vaccinated.”



“People with a compromised immune system may need a third vaccine dose to improve their response to the initial vaccine series.”



“Fully vaccinated immunocompromised people accounted for a large proportion of hospitalized breakthrough COVID-19 cases.”



“People who are immunocompromised are more likely to transmit the virus that causes COVID-19 to household contacts.”

# Navigating Vaccine Decisions

## One-Fourth of Patients are Not Fully Vaccinated

About three-fourths of respondents reported being vaccinated – 71% fully vaccinated and 3% partially vaccinated. About one-fourth, however, reported being unvaccinated. Their hesitation stemmed from a number of factors.



**Concerned About  
Vaccine Safety  
& Efficacy**

**60 respondents**



**Concerned About  
Side Effects**

**49 respondents**



**Concerned About  
Flare Ups**

**33 respondents**

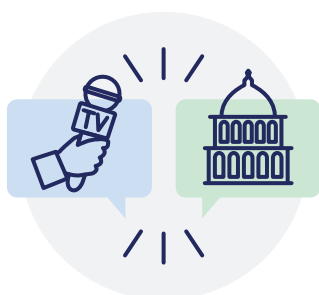


**Concerned About Having  
to Suspend Treatment  
for Condition**

**10 respondents**

## Mixed Messages Make Vaccine Decisions Difficult

One reason for the lag in vaccination could be conflicting information. Constant and evolving messages about COVID-19 and vaccination can overwhelm and frustrate patients.

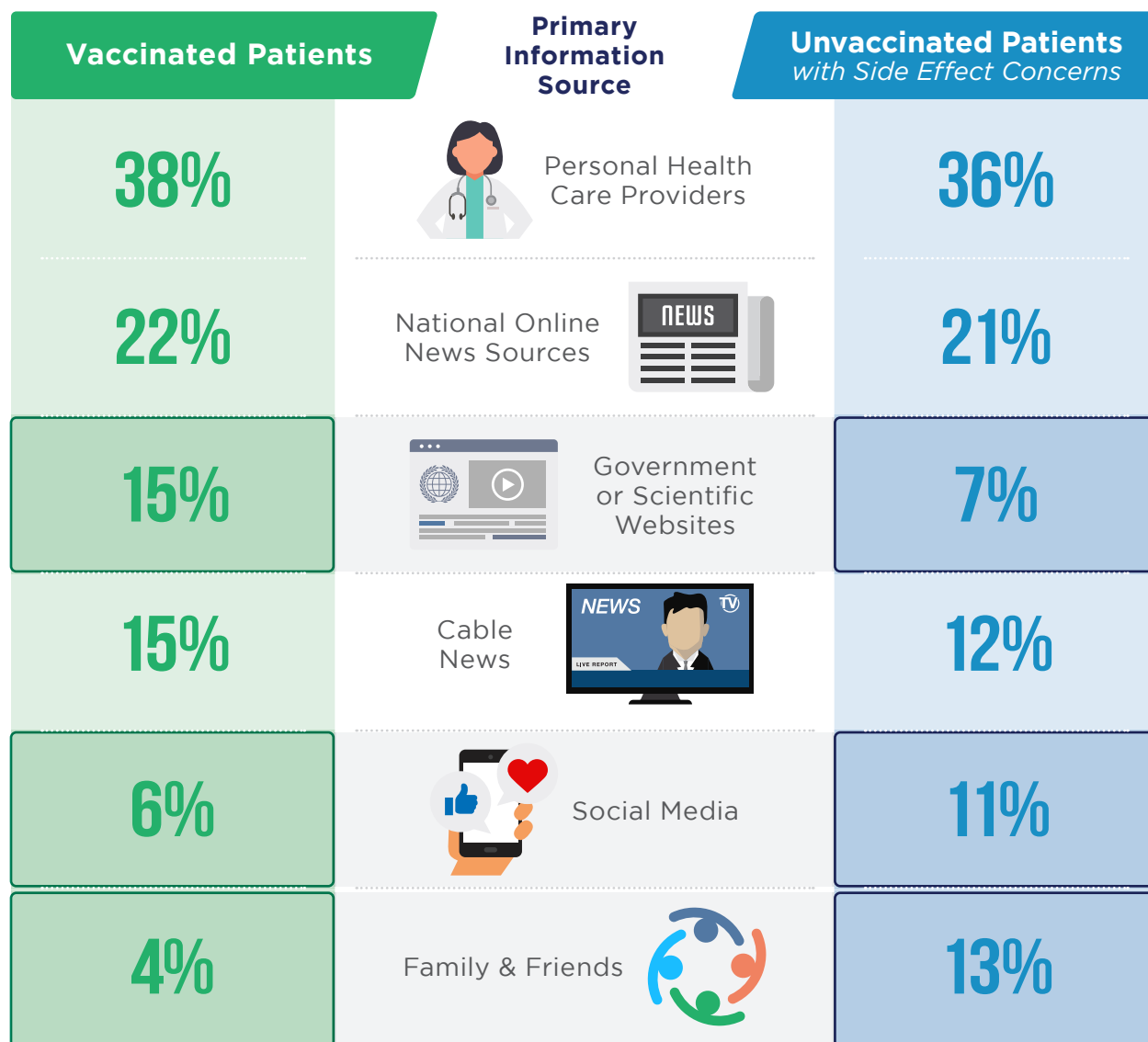


**88%**

**Mixed or unclear messages from the  
media and government complicate  
decisions about vaccination**

# Discerning The Facts

Patients' choice of information sources may impact their perception of vaccine risks. Unvaccinated patients concerned about side effects were more likely to cite social media and family or friends as their primary information source.



**“ People who contact us about COVID-19 often have anxiety due to misinformation online that lacks a strong scientific focus. ”**

– Brett McReynolds, Autoimmune Association

# Battling Uncertainty

## On Vaccination Details, Confusion Persists

For autoimmune patients, protecting oneself from COVID-19 requires navigating the details — the number of needed doses, timing of vaccine shots and whether the brand of additional doses must be the same as the original.



47%

Are uncertain about whether they need a third vaccine dose or when to get it

51%

Are uncertain about the difference between a third COVID-19 vaccine dose and a COVID-19 booster shot

47%

Don't understand if a third vaccine dose needs to be the same vaccine brand as the initial vaccine

Autoimmune patients want to find the best way to combine vaccination with continued disease management.



68%

Say COVID-19 vaccines are more effective with some autoimmune disease medications than with others

79%

Want to explore which medications for their condition are most compatible with the vaccine



**We get a lot of questions around how to time the vaccine shots with the medications patients use to manage their MS.**



*– Julie Fiol, National MS Society*

# How Policymakers Can Help

Moving forward begins with providing what continues to elude patients: clear, consistent and actionable information, preferably housed in a central location.



86%

“People who live with autoimmune diseases need greater awareness of the importance to get a third dose.”

93%

“People living with an autoimmune disease need easy-to-understand, factual information to guide their decisions about vaccination.”

Respondents also highlighted the need for policy that was tailored to them.

89%

“Government policies on vaccination should reflect the unique needs of people living with autoimmune diseases.”

## In Patients' Own Words

Free responses shed light on patients' experiences, frustrations and suggestions for improvement.

“Give out information that is consistent and accurate and comes from a single reliable source.”

“Be sure there are guidelines about people with autoimmune diseases who will take the vaccine.”

“Information should be sent to their doctors and the doctors should inform their patients.”

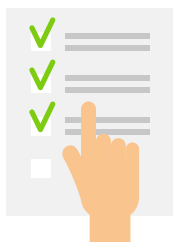
“Distribute clear and concise information to medical facilities for them to provide personalized, direct information to those with autoimmune diseases.”





# Needs Assessment

Survey responses, along with commentary from patient advocacy organizations, have given definition to what autoimmune patients want from policymakers. To manage their condition alongside COVID-19, autoimmune patients need:



## **Clear information about vaccines.**

Autoimmune patients express frustration and confusion when it comes to vaccination information they can trust and follow. They say guidance should be clearer, up-to-date and more easily understood.



## **Vaccine information tailored to autoimmune conditions.**

In addition to searching for current and reliable information, patients with autoimmune diseases must work to discern which guidance applies to them. Patients want clear information specifically developed for people living with autoimmune diseases.



## **Information that's accessible in a central location.**

Autoimmune patients express frustration with reliable COVID-19 and vaccine information being scattered. They would prefer information to be centralized in one reliable location.



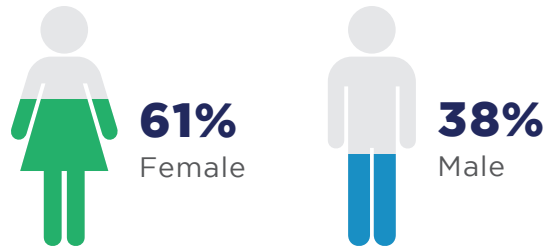
## **Health care providers empowered as sources of information.**

Autoimmune patients trust their providers to guide them with COVID vaccine decisions. They would like policymakers to better leverage providers as channels for distributing information.

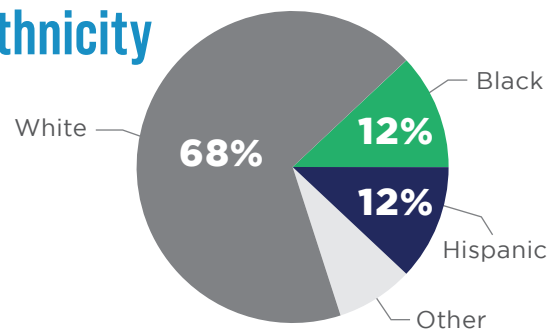
# Survey Demographics

Four hundred people living with autoimmune diseases participated in the online national survey between October 11 and October 19, 2021.

## Gender



## Ethnicity



## Age Range



## Autoimmune Diseases

Participants reported living with:

Rheumatoid Arthritis .....	60%
Multiple Sclerosis .....	17%
Graves' Disease.....	10%
Lupus.....	10%
Systemic Sclerosis .....	2%
Pemphigus .....	1%



## Community Distribution

Participants lived in:

Suburban Area.....	29%
Big City .....	22%
Smaller City .....	18%
Rural Area .....	15%
Small Town.....	15%

## Meeting Participants

On November 3, 2021, organizations that represent people living with autoimmune diseases met to consider the national survey data and the challenges facing patients during the COVID-19 pandemic.

### **Autoimmune Association**

**Arthritis National  
Research Foundation**

**Color of Crohn's &  
Chronic Illness**

**Global Alliance for  
Patient Access**

**International Foundation  
for Autoimmune &  
Autoinflammatory Arthritis**

**International Pemphigus  
and Pemphigoid  
Foundation**

**Lupus Foundation  
of America**

**Multiple Sclerosis  
Foundation**

**National MS Society**

**Public Health & Behavioral  
Health Policy Advocates**

**Scleroderma Foundation**



**Alliance for  
Patient Access**

The Alliance for Patient Access is a national network of policy-minded health care providers advocating for patient-centered care.

**[www.allianceforpatientaccess.org](http://www.allianceforpatientaccess.org)**